

[Return to NPL Web Page](#)[Text Version](#)

English

[?Help](#)

Collections	Search Methods	Topic Finder	Browse Lists	Results & Marked List	Search Guide
Searching collections: All Collections					Article Display

[Email Article](#)

Article 4 of 4

[Publisher Info.](#)[Print Article](#)☐ Mark article

Article format: Full Text

[Save Link](#) Saves this document as a Durable Link under "Results-Marked List"

Patient and physician responsibility in the treatment of chronic illness: The case of diabetes

The American Behavioral Scientist; Thousand Oaks; May 1996; [Rood, Robert Paul](#);

Volume: 39**Issue:** 6**Start Page:** 729**ISSN:** 00027642**Subject Terms:** [Physicians](#)[Patients](#)[Health education](#)[Health care](#)[Diabetes](#)[Chronic illnesses](#)**Abstract:**

Traditional medical education of physicians fails to adequately prepare them to deliver effective care to community-based patients with chronic illnesses. Rood proposes a more realistic disease model based on a humanistic approach to illness and the education of physicians.

Full Text:

Copyright Sage Publications, Inc. May 1996

The problem. The treatment models employed in clinical medicine, historically developed for acute illness, were never intended for use with chronic disease. Applying these models in such a fashion has met with failure and frustration. It is time to develop chronic-illness specific models.

This article looks at issues of chronic disease from the perspective of the illness itself, the patients who suffer from the illness, the physicians who are involved in the care of these patients, and the physician's training process that ostensibly prepares them to take care of these patients.

What are the goals of medical education and are educators aware of the needs and wants of patients with chronic illness? I propose a more realistic chronic disease model to educate physicians and to approach patients. The goals of this new perspective are to allow patients and physicians to be more satisfied with their treatment alternatives and more comfortable with their outcomes.

The case. It has often been said that chronic illness is the problem of the aged and belongs in the specialty field of gerontology. What about the teenager with ten years of unrelenting ulcerative colitis, the young married woman with 15 years of systemic lupus erythematosus, or the blind uremic man of 20 with 18 years of diabetes? These are not problems in the field of gerontology. These patients are young people who have to confront their illness every day knowing that a cure is not possible and a return to normality is only a painful fantasy. Their only reality is the betrayal of their body. These are the people who suffer daily. These are the people who pray silently in the darkness of the night for some type of truce, a respite, a time of peace.

As a practicing diabetologist for the past 30 years, I have been asked to initiate a dialogue concerning issues that facilitate or hinder physicians in their work with patients who have chronic illness. Physicians soon learn that the major characteristic that unites these patients is that they never get well. Chronic disease is chronic. There are better and worse days, but never a day free of the problems that confront them and their underlying ailment.

Most of the patients referred to me are acutely suffering from the complications of diabetes, others feel perfectly well; they are not bothered by their diabetes. They have no apparent complications. How does a physician get a patient to follow a treatment plan that is more bothersome to them than their disease? How does a physician get a patient to accept a strict diet, daily exercise, frequent self-monitoring of finger blood sugars, and multiple injections of insulin in order to possibly prevent pain and illness at some unknown point in the future?

I have chosen diabetes as the example for discussion primarily because this is my medical world experience and secondarily because it is a very common illness. Diabetes affects two distinct age groups and presents very different clinical scenarios and challenges. It is an unrelenting and unforgiving disease that requires major changes in lifestyle. Diabetes demands that patients maintain a constant awareness of changing physical and chemical conditions within their body, vigilance over the body's potential for betrayal. These patients never have the luxury of forgetting that they have diabetes; they cannot close their third eye. They have lost trust in their own biorhythm.

The simple act of injecting insulin repeatedly throughout the day is enraging. Each shot taken screams to these people that they are weird, weak, and imperfect. Their life is dependent on self-injection of insulin and this means that they are always vulnerable. The insulin-dependent diabetic patients exist in a daily precarious balance between life and death.

Even with meticulous attention to detail, things may go wrong and wrong things often lead to blindness, nerve damage, kidney failure, and amputation. This awareness and fear of body mutilation is so common it is often observed in the terrors of eight-year-old children who have had diabetes for only a few months. A simple cut toe or scraped knee too frequently evokes fears of a rapidly spreading infection and limb amputation.

Diabetes is a creeping malignancy that starts quietly and unobserved; it progresses to the point of illness and eventually kills the patient. Diabetes lasts from 20 to 50 years and during this long time frame, it can produce complications and progressive debility. In the United States, diabetes mellitus is the leading cause of new blindness, amputation, and end stage renal failure. It is a major contributor to myocardial infarction and hypertension. Death certificates may not list diabetes as a cause of death. In clinical medicine, the final insult might be biventricular congestive heart failure, but the real killer was the underlying diabetes.

Diabetes care differs from other malignant disorders in that 95% of the day-to-day management rests in the hands of the patient. The physicians are guides and advisors. This places a tremendous burden upon the patient for self-management and eventual outcome. Patients with traditionally classified malignancies are relatively passive within the therapeutic relationship. They receive treatment until either the malignancy goes away or they die from the treatment or from the spread of the malignancy.

One of the major challenges for physicians who work with diabetic patients is advice about appropriate treatment modalities including diet, exercise, self-blood sugar testing, and medication that may include oral agents, oral agents in combination with insulin, multiple injections of varied types of insulin, and alternative insulin delivery systems such as insulin pumps. Assuming that all of this information is provided, implementation is in the hands of the patient. The diabetic patient is in charge; their contribution to treatment outcome differs greatly from the role of the patient and the oncologist.

When new medical problems occur, they always interact with chronic problems. Everything gets worse when an acute problem complicates a chronic disease. A classic example of this is an elderly diabetic patient who falls and fractures a hip. The acute problem is the hip fracture and it is handled by the orthopedist in the operating room. The wound heals and the orthopedist's work is completed. For the orthopedic surgeon, the problem is over, the problem is fixed. For the patient and the primary care physician, the work is just starting. At best, rehabilitation is a long, slow, painful, and frustrating process. Often the long-term diabetic patient has been held together with bailing wire and chewing gum, a house of cards precariously balanced against the slightest breeze. Hip fractures often topple this precarious balance. All too frequently as physicians, we watch in horror as the patient develops the dwindles and then just dies.

The chronicity of long-term diabetes complicates every step of a healing process. Even with a good surgical repair,

the patient still has all of the previous problems attributed to chronic diabetes: the failing vision due to retinopathy, the loss of joint position sense and ataxia due to neuropathy, the ischemic limb weakness of vasculopathy, and the discouragement. The overwhelming sadness, almost a form of adult marasmus, stems partly from the realization that they feel abandoned, alone, vulnerable, and frightened. Once again their body has betrayed them and they will never be well again. For some people, life is too short; for others, life is just not fair. We know who takes care of patients who cry out with a bang. Who cares for those silent sufferers who may not even whimper? Who are the care givers? How were they trained? How did they learn the meaning of caring? How did they learn to give care?

The disease. Before we move any further in this discussion, I am going to beg your indulgence in reviewing some of the natural history of diabetes along with its chemical and the physiologic sequelae. I feel it is important to level the playing field so that we are all talking the same language and that the concepts developed will be understandable.

Diabetes mellitus is a chronic lifelong disease of glucose (sugar) metabolism. It can best be viewed as the inability of the body to properly utilize sugar for energy. Classically, diabetes has been divided into Type 1 or insulin-dependent diabetes in which insulin self-injections are mandatory for life, and Type 2, non-insulin-dependent diabetes where the patient may require insulin for maintaining glucose homeostasis, but usually can be controlled by the use of diet, exercise, weight loss, and oral hypoglycemic agents.

Although the two forms of diabetes share the commonality of abnormal glucose metabolism, the biophysiologic pathways in which these abnormalities occur are totally different. Diabetes 1 (Juvenile Diabetes) is an autoimmune disorder, in which the patient's immune system will eventually destroy all the beta cells of the pancreas. Thus there can be no endogenous production of insulin, which is required to move glucose from the blood into cells for metabolism. Without insulin, the cells are unable to take up this vital fuel and will soon starve and die. Although it is not a cure for diabetes, insulin does replace the missing chemical and these patients are able to lead active lives.

For over 60 years, there have been ongoing medical arguments: Can those who treat patients with diabetes make a real difference, or are they just hand holding until the moment of death? Do tight control and normalization of blood glucose levels prevent or minimize the complications of diabetes? Does normalization prevent blindness, kidney failure, extremity amputations, and death due to myocardial infarction? Are diabetic patients doomed from the moment of diagnosis to a life filled with incapacity, pain, and dismemberment? Are these patients aware of their probability for complications and how does it affect their compliance with treatment, their psychosocial health and interpersonal relationships?

Historically, research reported that diabetic patients also inherited a polygenetic profile that produced these complications. If this hypothesis was correct, then badgering these poor unfortunate patients into tight glucose control only produced unhappiness and neuroticism with little biologic benefit.

In an effort to answer some of these questions, the Diabetes Control and Complications Trial CCT 1993) compared the onset and severity of complications in tightly controlled Type 1 diabetics to standard care matched patients. The DCCT has clearly demonstrated that tight control does prevent complications. The ethics oversight committee terminated this study prematurely due to the high incidence of renal, neural, and ophthalmologic complications seen in the standard care arm of the experiment compared to the tightly controlled population. Standard care was defined as the usual care given to diabetic patients in the United States and it turned out to equate to poor glucose control.

However, to obtain effective management of Type 1 diabetics, the study relied heavily on psychosocial intervention. The normalization of blood sugars required frequent contacts with concerned individuals, and thus the relative importance of insulin compared with psychosocial support is not clear. Which of the component treatment modalities employed in the DCCT research protocol had the greatest effect on outcome? How does one effectively change the ways in which community-based physicians care for their diabetic patients in order to obtain a healthier outcome?

Diabetes 1 must be viewed as a disease in evolution. It is an insidious disease that may take several and often many years to manifest itself. There is progressive destruction of the islet cells of the pancreas until critical beta cell destruction severely curtails insulin production. Symptoms associated with hyperglycemia may wax and wane until glucose levels remain markedly elevated. Once this state is reached, symptoms rapidly escalate in severity.

An example of this "clinical evolution" of diabetes is seen in the unconscious 3-year-old who presents in the emergency room. Diagnoses of meningitis, poisoning, and/or intracerebral bleeding are usually made, only to be discarded when routine laboratory tests reveal the presence of diabetes. In retrospect, the parents did notice an

increase in bed wetting and an irritability of their child over the past few months. They also noticed a change in eating patterns and even a loss of weight. Some of these children had been brought earlier to their pediatricians and had been diagnosed with "the flu." It was not until the child was unconscious that diabetes was discovered.

Most physicians and patients believe that once diabetes is diagnosed, it never "goes away," that the pancreas has no capacity to manufacture insulin, and the patient will always be totally dependent on insulin injections. This is true for most but not all Type 1 diabetics. The course is variable. In some patients with Type 1 diabetes, the pancreas continues to produce small amounts of insulin over the course of their entire life and helps stabilize blood sugars. For others, there is a "honeymoon period" when the pancreas is able to produce enough insulin to allow the patient to "come off" insulin. The time period for this honeymoon is variable, and when it is over, insulin injections are once again required.

The oblique reference to a time of joy and sensual pleasure ending with the crash of reality, suffering, and dependency may only be euphemistic, or possibly it gives modern physicians an intimate glimpse at personal experiences not intended for public view.

Philosophically, children and young adults afflicted with Type 1 diabetes are "innocent"; they did not cause their disease. It is not their fault. Genetics is seen as the root of this disease, and genetics implies culpability and subsequent guilt on the part of the parents. Parent will usually turn against parent to lay blame. Family trees will have their limbs searched in order to attribute relative culpability. Fear for the child's diseased future mixes all too readily with the shame and guilt of causation. The parents often retreat into silent hostility, focusing their efforts toward having their child become the best-controlled diabetic in the history of medicine.

During the first three to five years after the initial diagnosis of Type 1 diabetes, glucose levels are usually easily controlled and the glycosolated hemoglobin A-1c blood tests show that the average blood sugar levels are normal. If the patient is a child, he receives praise from parents and doctor for such good work. He garnishes accolades for being a "good diabetic" and is often signaled out as an example of maturity and self-responsibility. Physicians and parents are proud of their accomplishment with their good little patient. Everything is rosy, bright, hopeful. The worries that parents have for their child's immediate safety diminish and their fears concerning the eventual loss of vision, limb, and other potential mutilations recede from their constant thoughts.

Frequently within five years, their previously well-controlled child appears to run amuck. Glucose control unravels. The degree of family personal involvement is incredible intense. The family screams and accuses the child of cheating on his diet, of not caring about his future, of destroying all the hard work that the parents and medical staff had done for him in the past. The family becomes confused and frightened. The family becomes angry.

The physician becomes angry. The medical authorities pontificate "adolescent rebellion" or even "pre-pre adolescent rebellion" if the medical system cannot force the patient's chronologic age into a convenient cubbyhole. The medical team becomes frustrated and accuses the child of cheating; the child denies. Blame is clear, blame is loud, blame is pointed. "The child refused to be compliant with the medical program."

The dietitian re-educates, the social worker re-socializes, the psychologist psychologizes. Chaos rules. Emotional terror splinters the family. Diabetes control issues dominate dinner table "relatedness." Helplessness, fear, and anger prevail. There is only one commonality: No one is happy. The child retreats in shame, in silence. The child loses the praise of his parents and of the medical authority figures. He is no longer the proud model of the medical educational system; he is no longer "our good little diabetic."

Medical teams working with these patients should realize that most of these young patients have not rebelled against their diabetes. They have not changed their eating patterns, their exercise activities, or their attitude. They have just become totally dependent on the exogenously injected insulin, and this total dependency produces a roller-coaster ride of high and low blood sugars as activity and lifestyle interplay with insulin injections.

Although insulin therapy is the cornerstone of treatment for the Type 1 diabetic, it is not without its risks and problems. The DCCT clearly demonstrated that patients taking multiple injections of regular insulin per day (intensive insulin therapy) have better glycemic control, but they also experience a much higher rate of significant hypoglycemia. The nonphysiologic action of injected insulin compounds the problem. Self-injected insulin is subcutaneous and its absorption into the bloodstream is erratic and unreliable. One day the insulin absorption is rapid and the insulin acts "hot" and acts rapidly. On other days the absorption is so delayed as to act as if it was never taken. "Cold" insulin has little physiologic effect and the blood sugars climb rapidly to great heights. Thus total reliability on insulin injections for blood sugar control is an impossibility. When the body's physiologic backup of

insulin secretion is exhausted, the patient becomes a bouncing ball of glucose levels.

Further glucose instability is experienced when psychosomatic hormonal forces affect glucose balance. Emotions through the hypothalamus can produce giant swings in blood glucose levels. A patient who is agitated, angered, or fearful produces adrenaline for the fight-or-flight response. The chemical triggers the release of large amounts of stored glucose from liver and blocks the action of insulin. Thus, the end point of stress is glucose instability. Stress will raise blood glucose levels and these high glucose concentrations may act as a tranquilizer. Many patients report feeling emotionally better with higher blood sugars. They prefer this semi soporific state and will be very resistant to lowering their blood sugars. Patients report, "This is my normal blood sugar," "I do not feel good at blood sugars under 200," "When you bring my sugars below 150, I have low blood sugar reactions," (hypoglycemia equates to loss of life control). These low sugar reactions can be experienced as shakiness, tremors, headaches, loss of clear thinking, loss of reasoning, loss of motor control, sleepiness, syncope, unconsciousness, seizures, and, rarely, death. Some patients are so fearful that they will not aim at normalizing their blood sugars for fear that they will go into hypoglycemia and lose bodily or emotional control. They will not risk physical injury or embarrassment. No degree of discussion or education will make these patients change their minds and behavior.

Varied meanings of normal. Responsibility for one's own diabetic management is such a heavy load that it often breaks spirits, depresses, and leads to denial. During the first ten years of the day-to-day life of a diabetic patient, there is no pain, no discomfort, no outward sign of dysfunction. "I feel fine" says the patient with diabetes chronically out of control and blood sugars in the tissue-toxic ranges of 300. Since they feel fine, why should they worry about tomorrow? It may never come. Chronically elevated blood sugars, two and three times normal levels, rarely produce short-term symptoms and these values are frequently acceptable goals of glucose control for many physicians and patients. These physicians fear low blood sugars almost as much as their patients. As long as their patients are free of the annoying symptoms of elevated blood sugars (thirst, frequency of urination, nocturia, and weight loss) and are free of any symptoms of hypoglycemia, they feel that their job of managing diabetes is well done. The patients feel well today, yet their bodies are quietly deteriorating from these "acceptable" high blood sugars. The price of chronically elevated blood sugars will be paid at a later date. Also, there still remains a small percentage of diabetic patients who will develop complications despite tight glucose control. These patients have a disease that appears to do its own thing. I have seen diabetic complications gallop on unaffected by any treatment program.

When complications occur, there is so much anger floating around] The patient immediately blames himself; the doctor usually blames the patient. The patient explodes with fear, rage, impotence, and a broken spirit, now at the disease and at the medical profession for letting them down. They had faith that medicine would take care of them. They remember bitterly doctors who promised new breakthroughs in research at any moment. They remember the empty slogans that promised a cure for diabetes within their lifetime. "Where are these miracles, these cures when I need them now?" Did these patients hysterically believe in empty promises, or did physicians offer promises when they had nothing else to give?

Public regulations may be a disincentive to normal blood sugars. Diabetes still carries social and economic stigmas. Insurance companies generally will not insure insulin-requiring patients regardless of their state of health or perfection of glucose control. The historic track record of increased need for services and the accompanying financial risk block access to health insurance coverage for patients who need these services to stay well. Most companies automatically reject an application for health insurance from any person who takes insulin; although a few will offer benefits at astronomically elevated premium rates, they exclude any claim that appears related directly or indirectly to diabetes. Life insurance can be bought at inflated rates for very little coverage.

Motor vehicle departments ask about diabetes on drivers' applications and patients often lie from fear of rejection or unending bureaucratic hassle. Patients who attempt to control their blood sugars within the normal range might experience hypoglycemia while driving and might cause accidents. Drivers' licenses are suspended or revoked, and patients are thus encouraged to keep their blood sugars elevated. Most patients with diabetes would rather sacrifice their future health and well-being for the ability to drive an automobile. Diabetics who take insulin cannot be airplane pilots and intrastate trucking regulations prohibit them from this form of employment. Diabetics cannot join the military, scuba dive, operate "dangerous machinery," or perform countless other jobs in industry.

The fears of prejudice, discrimination, job restriction, loss of insurability, loss of self-esteem, loss of autonomy, loss of function, future disability, and even death hover continuously within the thin veil of the preconscious. Patients with diabetes have to constantly test blood, shoot shots, eat diets, exercise limbs, watch for infection, watch for deterioration, watch and watch and watch. There is no escape, there is no "have some one else do the work and carry the ball." The full and total responsibility for success or failure appears to rest with the patient.

Recently, I was making rounds in a hospital when I overheard a nurse instructing a newly diagnosed diabetic. She clearly and repeatedly told this patient that the responsibility for managing diabetes clearly rests with him. Insulin injections had to be taken at precise times. Ice cream, candy, and "goodies" were dangerous and had to be avoided at all costs. Rest periods throughout the day were imperative to avoid bringing on exhaustion and illness, and life from now on had to be one of responsibility and self-discipline. If the patient didn't do all of these things perfectly, he would become blind and/or lose a leg. I pulled back the curtain separating me from the nurse and her patient only to discover a little boy of six years sitting on the edge of his hospital bed, rocking back and forth and sobbing.

What is the meaning of chronic illness to a six-year-old? Where does he go for understanding and compassion? What are the psychological sequelae of so much responsibility so soon in life? Where is his lost childhood, and what is the price of this loss? What is going to happen physically to this lovely innocent child in the coming years? Can we, the medical profession, protect him from becoming hurt and dismembered?

Insulin treatment programs as prescribed by most physicians provide looser control. They are effective in keeping patients alive but not in preventing complicating organ failures. Are we willing to share responsibility for outcomes with patients, or is it solely their ball to carry?

In their anger with patients who will not take care of themselves, some doctors try to scare their patients into compliance by showing them horrible textbook pictures of gangrene, amputations, and renal dialysis machines, as if these graphic displays will "change their patient's bad habits and evil ways." Physicians fail to understand that these images are with these patients from the very first day of diagnosis. Fear is overwhelming; fear is paralyzing. Fear is angst. Pictures do not educate; pictures perpetuate panic. Fear can only be treated by the physician with tenderness and with acceptance.

The physician as a teacher, a guide, and a friend. Openness and love encourage a closeness between patient and physician so that they are free to travel the path together, not as parent and child, but as two adults each bringing to the relationship a uniqueness that is healing. It is only within the safety of this relationship that a patient will feel free to express his feelings, his fears, and his fantasies. The physician is not a puppeteer sitting on high and manipulating the patient's strings. No doctor should have such audacity, such self-indulgence, such sense of omnipotence.

Despite recognizing intellectually that no one is omnipotent and no one can control another, most physicians still want to control patients. They believe emotionally that they have the power to direct outcomes. To the average physician, rage at the progression of complications of diabetes in Type 1 reflects their own impotency. Physicians are taught that they can conquer disease. Most believe in themselves and their power. Yet when they are impotent to affect an outcome, their response often is rage at the patient, the disease, and themselves. Repeated "failure" is not tolerable, because to some physicians failure is personalized, a reflection of worthlessness, and they cease being involved with their patients. They become angry, hostile, and combative.

They also hope that research concerning new treatments, genetic predictors, and islet cell transplants will cure diabetes and prevent its occurrence in future generations. Frustrated illness treaters want the right formula so that they can give health. Physicians want to change the model from chronic illness to acute illness so that they can feel the thrill of success. Implant, supplant, replace, manipulate genes, diet, and medications. Early detection, preclinical detection, immune intervention, vaccination, there is no limit to what we can do ... to them, for them, with them. Hurry] There is not time to waste. The enemy is seen. Medicine can beat the enemy. Medicine has the power to cure. This is where we are comfortable because it is here that we have been successful. There is a burning urgency for physicians to regain control.

Many patients do not listen, and if they do listen, they act as if they do not hear. In the past, they have heard so many empty promises, they have held tightly to so many false hopes, that the pain is too great. They push away what they perceive as the false prophets of organized medicine so they can be free, yet the freedom brings with it a panic of abandonment. They run from the fears of complications only to return broken and in need of temporizing high-tech treatment. What patients want is a trusting relationship with their physician, one that will be therapeutic to both mind and body. They want to be understood and accepted. They want interaction and technical competence. So often what they get is lectures and distance, the two disciplines that were so thoroughly taught to physicians in their training program.

Type 2 diabetes, the ultimate physician humbler: Eighty percent of all diabetes care does not involve the glamour of working with children and young adults. Most diabetics are Type 2 and they are usually older, overweight, and under-exercised. The pathophysiology of this form of diabetes is initially the overproduction of insulin, or insulin-like

products, by the pancreas.

The long-term diabetic complications of Type 2 diabetes occur when blood sugar and insulin bind with circulating proteins to obstruct blood flow and to produce tissue hypoxia. The organs suffer both from a lack of energy and from ischemia. Paresthesia, painful neuritis, strokes, TZAs, angina, retinal hemorrhages, proteinuria, hypertension are the cries of ischemia. Diabetes can be best described as a piecemeal autopsy—a series of deaths of parts until the owner succumbs to "no more parts."

The physical appearance of most Type 2 diabetic patients rarely engenders prolonged sympathy from the medical staff. These patients are usually either simply overweight or grossly obese. They are overfat and underexercised. They love to eat. They live to eat. They die because they eat. Most want to try to change their habits; few do. They cannot exercise due to obesity and deconditioning. Medication may have little effect in significantly lowering blood sugar. The cornerstones of treatment are diet, weight loss, and exercise. The medical staff's attempt to motivate usually fails after a brief show of progress. Many of these patients are like giant boulders. It takes a herculean effort to get them to move. They finally rock out of their hole in the ground only to balance precariously on the edge and then topple back into their previous resting position. The staff tries again, but eventually they become frustrated and angry; they become apathetic and symbolically fuse with the apathy of the patient.

One bizarre luxury of being an older physician is that I have seen these clinical vignettes played out over and over again. Enthusiasm, frustration, anger, and eventually apathy are the treatment team's responses to the overweight Type 2 diabetics. They do not view these patients as innocent victims of a genetic disease. "It is their obesity and inactivity that has brought on diabetes and has led to their medical problems."

Commonly physicians, dietitians, and nurse educators begin their interaction with these patients with a prejudicial bias and a conflicting hope. "I take one look at the patient and know that we are going to lose." "Even though I believe most patients will never change, I still go through the routine and hope that possibly one will surprise me."

Despite these prejudices, the metabolic team does what it has been taught to do—they educate. To educators, education is salvation. They believe that these patients just need to know the facts, the consequences of their behavior, and this information will lead to changed behavior. The treatment plan is simple and straightforward: they will have to go on a strict diet, to lose half of their body weight, exercise, stop smoking, and embrace healthy living. These are the keys to controlling Type 2 diabetes. It's all in the book, on the tape, in the classroom. Support groups abound. Teachers teach, lecturers lecture; patients remain unchanged.

Why don't these patients listen to reason? Why can't they learn what is taught? Why do they refuse to follow medical direction, instruction, and treatment plans? Why do they make contracts with us for performance and constantly disregard what was promised? How can they claim to stick to the diet plan and gain three pounds with each clinic visit? We work so hard with them and it does no good? Why do they insist on hurting themselves? Does noncompliance equate to abdication of rights to future care? Why should we continue to do vascular procedures, dialyze, expand scarce or expensive resources on patients who are noncompliant? Why should marginally viable extremities be operated on when amputations are quick, sure, and cost-effective? These are the thoughts of many care givers, both physicians and hospital personnel, that are rarely spoken out loud but only muttered within apparently secure confines of coffee rooms:

Send these bad patients to psychologists.

Lock them up.

Stop them from eating.

Staple their stomachs.

Wire their jaws shut.

Food is killing them.

The frustration on the part of the medical system in working with the majority of Type 2 diabetics is painfully simple; these patients generally do not change their behavior. Education has been shown to create knowledgeable noncompliant patients. People will only change their behavior when they get more pleasure from the new activity than from the old. Some are immobile because they carry their neurotic past with them as heavy chains and

shackles. They realize what they should do, it's just that usually they cannot.

The Type 2 diabetic patients are usually older and have had more years to set their ways. Overeating and little exercise are the main contributors to obesity, which in turn leads to the uncovering of genetically determined Type 2 diabetes. Very few obese people have failed to recognize that they are obese; fewer have never attempted to lose weight. They have gone on diets and they have failed.

Psychologists have theorized that these patients obtain oral gratification and that food is a tranquilizer: they eat because it feels good. They do not lose weight because it causes them discomfort. Loving, supportive encouragement to lose weight fails because food is a greater pleasure. Noncompliance with a treatment plan is to be expected; compliance would be unsettling. The diagnosis of diabetes is just another "burden" that has been piled on them. The diagnosis of diabetes is not a call to action, for nothing is a call to action. Interventions are useless; they need an extensive psychological make-over. Without approaching the main pathology, all the education and support is a total waste of time.

I realize that this attitude will anger the educators, the social workers, and the physicians who believe that through love, support, encouragement, and even threats, the Type 2 diabetic patient's behavior can be changed. Well, all of these techniques have been tried by medical teams, and they have all failed. This doesn't stop the newest crop from trying to devise a new and innovative method for obtaining compliance. The latest copies of Diabetes Care or Diabetes Educator will certainly have an article or two on the newest and best method of empowering patients so that they will take charge of their diabetes. Empowerment is described as if it is a commodity that can be given to people. In the real world, empowerment comes from ego strength and a sense of self-worth.

The Type 2 diabetics who do not do well in treatment generally have no strong feelings of self-worth prior to the onset of diabetes. They commonly obtain their validation from outside sources. They ingest their pleasures. They use food as a tranquilizer. What system yet devised can override this self-gratification and constant stimulation of a pleasure center?

Often they have functioned with the belief system that life has not been fair to them, and diabetes is further proof that their belief system was right. They didn't ask to have diabetes. The diabetes may be discovered by accident on a trip to the doctor's office. A male patient may have been forced into the medical office for a routine physical examination by his well-meaning wife or mother. He didn't want to be there to begin with. He finds the medical system annoying. Preventive medicine is not a part of his mind-set. "If it ain't broke, don't mess with it." He has no complaints. He feels no pain. He is not dys-eased. Now he is told by a doctor he didn't want to see in the first place that he has diabetes; so what? He is told to change his lifestyle to prevent something that might or might not happen in some future time. He is told to give up his beer, his predinner cocktail, his favorite foods, and the pleasures of a good meal. The patient feels that he has earned the right to eat well. He has worked hard all of his life, he has raised a family. He has given to others before taking for himself. His main pleasure in life is a good meal. "You want me to give all of this up for the ability to live longer? Who wants to live a long miserable life when I deserve the pleasures of life now? Why must he be inconvenienced now when no one knows what the future will bring? Live for today. "Look, Doc, I don't know about 20 years from now, I don't even know about tomorrow."

Most patients do not have the capacity to tell the physician to go away. Few patients have the ego strength to tell the medical system that they are personally responsible for their own health and that they choose not to follow the medical "treatment plan." When it comes to food, exercise, weight loss, and giving up reliable sources of pleasure and comfort, most Type 2 diabetics feel that it is them against me. Instead of clearly stating their preferences, these patients mutter, "I'll try." They try; they fail. Now they have to report back to the medical authorities, to the father, to the police. Failure is intolerable; avoidance is more reasonable: "I'm too busy, I forgot the appointment." Anger is there, at himself, at others, at the system. Anger is not nice, it produces tension. Anger is not socially acceptable, therefore it has to be changed into another form. Anger soon becomes passivity. No one can accuse him of being hostile. He is contrite; he is quiet; he tries. Trying is different from promising. Trying allows for a way out.

How can a health care professional change a patient's behavior? What works? The simple answer is "I don't know]" The frustrations of working with the Type 2 diabetic are well chronicled in the medical literature; everyone knows what doesn't work. Recently, this clinical presentation has even been elevated to the term "Syndrome X." In this clinical picture, there is obesity, diabetes, hyperlipidemia, and hypertension. Now that we have categorized it, so what? Medicine has always felt empowered by the act of description. Name it whatever you want; the problem remains the same. The reality remains the same: Lose weight and Syndrome X will cease to exist. Support groups, diet groups, psychologic groups, and frequent physician and physician's staff contacts all work for short periods of time. Patients lose weight, plateau, break treatment, regain weight. Each patient represents the thousands of

pounds of weight lost and regained throughout a lifetime of trying. If this accounting accurately reflects the real world within the community, it is appropriate to look at formal medical education and see if its perception of the skills and training of its graduates is appropriate for delivering effective medical care. How can future physicians be prepared for this brutal reality?

During the last 20 years, there has been a growing dissatisfaction with traditional medicine. Patients perceive that their needs are largely unmet or considered trivial by organized medicine. They do not want to be seen as a statistical widget but as an important human being in need of care and consideration. Alternative medicine and its practitioners appeal to patients in evergrowing numbers. Under all of this controversy lies a very difficult question. What constitutes a good physician?

Formal medical education: goals and objectives. Ask this question of patients and the most frequent answer is someone they can talk to, someone who listens to them, someone who is available to them, and someone who can make them well.

Ask the same question of university medical residency teachers and the list of characteristics is often much shorter. A well-trained individual with clear analytic skills; a person who is fully knowledgeable in his or her chosen segment of medicine and capable of directing medical care for a diseased patient.

Ask the same question of a graduating medical resident and the answer reflects the university philosophy with additional modifiers. "The physician knows what the patient needs." They will not let the disease beat them. These physicians often scoff at the apparent bumbling and incompetencies of community doctors. They value knowledge of diseases and their treatments as being much more important than listening to patients. Ten years later, many of these same physicians shift their responses to this question and embrace interactive listening as an important part of the healing process.

But medical schools continue to teach disease recognition and treatment, not patient care. Diseases stand alone as singular entities and not as illnesses affecting the lives and lifestyles of those afflicted. Medical professors, the teachers of these future doctors, are chosen for their knowledge of specific disease entities. The neurologist educates students about nerves and their disease, the endocrinologist teaches about diabetes, the orthopedist teaches the techniques of amputation. No one teaches young physicians about the care of the 45-year-old Latino day laborer who has diabetes, severe neuropathy, and an infected osteomyelitic foot. A man, a father, and a husband who will lose his leg to amputation and never work again. Who teaches total integrated care? No one who matters] How much time is devoted to this subject in medical school? Possibly one unit of lecture time; one hour out of four years of formal education. One hour that no one considers really important.

Disease and dys-ease may sound alike, but in the real world, they are poles apart. During the second half of medical school, students are introduced through clinical rotations to living examples of textbook slides and overheads. The individuals so afflicted are simply the vectors that bring the disease into the presence of the medical establishment. Emphasis is now subtly shifted from memorization to the "diagnostic process"--the formalized medical school equivalent of cognitive awareness. It is amazing: "Someone really can have the same thing we learned in pathology." Thus it is commonly heard in coffee rooms: "the gangrene appendix in room 6" or "the stroker in bed 5." No name, no identity, no personhood, just a disease to be studied or a diagnostic dilemma to be solved.

Medical school graduation signals the first cut in the physician education process. Those students who are recognized by the academic staff as possessing outstanding minds are encouraged to stay on at the university and to enter pure medical research. The medical university perpetuates the notion of science as the legitimate answer to all questions. They continue to measure their status by the success of their research departments. University medical centers have become the temples of truth, and they elevate the super-specialist to the priesthood. My own medical university was located on Mount Pamassus.

The realization that clinical physicians are not scientists appears to have escaped the university. Physicians use the discoveries of science as a tool while interacting with people in both sickness and health. A physician is both a teacher and a healer. Issues concerning ethical and moral values, rights and obligations of or to others must stand equal with accuracy of diagnosis and treatment of disease. A physician has a moral obligation to his patient that goes beyond science. Outside the department of psychiatry, the patient-doctor interrelationship has never been taught properly at the university. University medical education has always emphasized disease diagnosis and treatment.

At most university medical training centers, the academic educational staff feel that generalists are not the proper role models for medical students and have little to add to educational excellence. Generalists represent the parish care givers waiting for their directions from on high. They are the hand holders; the health care givers that have little to offer in the form of meaningful contribution to the medical team. In the old days, there were only a handful of diseases, for which there were less eases. Now, with the rapid influx of clinical and basic scientific discoveries, medical educators pose the question: "Do you want to know very little about a lot or everything about a specific area of medicine?"

The medical residency training curriculum is a series of specialty sections where once again the disease is the important focus. The physician's knowledge of the disease process and the selection of the right treatment is of paramount importance. The patients are nonissues when they comply or the enemy when they don't. "I cannot believe the patient deliberately screwed up my perfect treatment plan." "If he continues not to follow my orders, I want him transferred out of my clinic. Let someone else worry about him (get stuck with him). He is just wasting my valuable time." "His continued self-destructive behavior makes a mockery of what we have to offer. He abdicates his right for medical care." "We have more important things to do for more deserving people, people who want to help themselves and therefore are more deserving (appreciative) of what we offer."

The residency program acts to shift the young physician's attitude from disease to patient management and disposition. Unending numbers of people converging on the medical center at all hours of the day and night. Heavy schedules, long hours, unending lines of patients in clinics and wards. Unending diagnostic challenges dropped on doorsteps at unholy hours of the night. Evaluate, diagnose, treat, dispose. Keep the line moving. Do not clog the system. Off-load before the weekend. People always get in the way. If caseloads are not handled quickly, there will be less time to sleep. A stroke patient unconscious without a family member is ideal. An ancient woman with a fractured hip who speaks no English is a godsend. It is clear what has to be done: fix the fracture and send her to rehab so someone else can worry about final disposition.

The residents have an opportunity to rotate through the outpatient clinical division to learn primary care medicine. The patient volume is high. Charts are thick and often multiple. "Familiarization" must be rapid. Patient's parts are rapidly examined, medications reviewed, new prescriptions given and older ones reordered. "Return in 6 to 8 weeks" is the usual chart notation because the resident knows that he will be back to the security of the medical wards in four. What is the real value of this clinical experience? What does the young doctor learn about the meaning of long-term care of the chronically ill?

To the physician who is about to graduate, university medicine is challenging, important, and appears to be the only real medical world. For many, their competency lies in technical skills and they have had inadequate training in primary care. Often, academicians consider primary care physicians as hand holders who take care of well people. "They could be replaced with nurse practitioners or bleeding heart social workers with the same or improved outcomes."

The completion of the residency program gives the university medical center one last opportunity to keep the most promising residents within the academic fold. A select few are offered clinical teaching positions and are encouraged to do clinical research, teach residents, and see a limited number of private patients in their own clinic. The remainder of the residents are bade farewell and forgotten. One month after completing my residency training, when I was a locum tenets for a community doctor, I had an opportunity to refer to my medical university a young man with diabetes, hyperosmolar nonketotic stupor, and previously undiagnosed acromegaly. Later when I reviewed the patient's hospital record, I discovered, to my chagrin, that I was referred to as a local medical doctor (LMD), the inference being that I had accidentally stumbled onto this diagnosis. The medical resident gave me credit for referral to the university for proper management. This problem was "certainly too complex for an LMD's care." One month and 5 miles away from my senior residency position, the university considered me a "nobody."

The practice of medicine at the university is not the real world. The residents and professors have no idea what constitutes a real clinical setting. They have no inkling of the intensity and commitment that exists in a patient/physician relationship. They are pretenders; onlookers from their isolated positions of authority. They don't get their hands dirty in the complexities of their patients' daily lives.

Physicians who choose to leave the security of the medical university and enter into full-time, community-based clinical medicine have to discover on their own what really matters to patients who inhabit a real world. Through trial and error, these physicians come to understand that their role in the health delivery system is much different from what they were taught in their medical residency program. They have to learn painfully that their medical treatment plans are often inadequate when measured against the wants, wishes, and needs of their patients. No longer are

these physicians going to be assigned to a clinic for 6 to 8 weeks and then move on. Their patients are with them for long periods of time, and their medical problems are often tightly interlaced with social and family issues. Various cultures view health and dys-ease differently and the competent physician has to be sensitive to these forces. Often, with great frustration, physicians have to discover how to create, contact, and implement health care measures that are realistic as well as medically sound. No longer will a patient be simply the vector of an interesting disease. The physician will have to learn how to deliver health care that integrates the health belief systems of the patient, the family, the culture, and the community. Physicians now have to assume multiple roles because the patients look to their physician for care and not just referral to a "someone else." Patients expect that their physician will know them, understand the multifaceted aspects of their illness, remember what works for them, and be there to help solve problems when they arise.

Residency teaches how to treat disease; primary care within a community setting teaches long-term responsibility to patients. Concerns relating to the issues of how much, how far, and to what goal now enter the therapeutic equation. "How do I best serve and treat my patient?" becomes a legitimate question standing alongside the question of how best to treat the disease.

Medical residents have little experience with long-term ambulatory patients who have chronic illness and still live outside a hospital or residential setting. "How much longer will I have to endure the indignities and dependencies of this illness are words expressed by patients to their primary physician. Where are the textbooks of answers? How do we handle the whimper when we are so skillful in handling the bang?

The development of the skills of a practicing community-based primary care physician requires the acceptance by the physician of a sense of vulnerability, and an abdication of omnipotence and omniscience. Residency training developed and honed the skills of diagnosis and treatment within the confines of the acute hospital setting. This was acute care of the seriously ill. Mistakes were not tolerated; errors in judgment were shameful. Fear drove young physicians in training to do the right thing, to know all of the answers, and to strive to control all of the variables. The patient was the vector housing the enemy. The physician was the might, the sword to vanquish the enemy. Disease had to be beaten regardless of the price.

Within the clinical setting of a primary care physician's office, patients often present with ill-defined concerns and worries. They do not come as vectors of disease but as human beings, frightened and vulnerable. Some clearly show their fear, others their anger and resentment. Some issues that worry patients appear trivial to the physician while other medical conditions could easily be handled if only the patient would follow instructions. It's the chronic medical problems, the ones that will not go away, that cause the most frustration. These are the conditions that will not respond dramatically to the powers of medical research. Do we make a difference when we interact with patients who have long-term chronic illness? Are we, the health care team, of any value to the patient and family? Who is in need of care, and what form should this care take?

Cultural and community influences on **chronic** disease. **Patients** with **chronic** problems bring with them not only their physical and emotional pain but also their cultural and community values that influence both their perception of illness and their response to **treatment**. For some **patients**, the past is the important time frame. They come with signs of historical **treatments** such as herbs pressed against their **skin**, or signs of cupping. It is at first frustrating to the university-trained physician to see a **patient** with sepsis and gangrene of the leg covered with cupping marks. Why did they wait so long before seeking **medical care**? Why are they so quiet and passive?

In reality, most of these patients did not deny their illness, nor did they delay seeking treatment. They first went to the family for help, then to the religious or cultural healers, possibly even to the pharmacist, and only last to the doctor. It is no wonder that often when these patients present with widespread and advanced disease, amputation may be the only life-saving procedure available. This mutilating surgery will certainly turn the family's hardworking food provider into a nonworker. For this laborer, losing a limb means that he is now a cripple. He had his leg before he went to the doctor and now it is gone. See what they did to me? For this man, loss of dignity and importance will never be forgotten. In his eyes, going to the doctor was going to result in great harm, and it did. We try to reason that the harm was caused by the delay in seeking treatment. They only came into the medical system when their cultural medical model failed. Seeking medical care from an outsider means that they have lost dignity, they have lost faith in their time-honored and traditional system of healing.

A second group of health beliefs relate to urgent medical problems, the "now" complaints. I have a nail in my foot, and I come to the doctor to stop the pain so that I may continue with my activities. If during your treatment of my painful foot you accidentally discover that I have diabetes or hypertension, why should I be forced to take medicine for the rest of my life? This disease is not important, it doesn't interfere with my work, my play, or my family life.

Don't tell me that taking medicine every day will keep me healthier in the future years. Who knows what these years will bring? I may remain healthy regardless of what you say. I live in the now and present. Preventive medicine is meaningless.

When does a physician cease parenting patients and begin a new learning experience of interactive listening? What are the evolutionary steps that allow physicians to become tolerant and resolve their own frustrations and anger at seeing patients destroy themselves? Is acceptance of patients' apparent foibles and weaknesses a sign of physician weakness? Does the weakness of one reflect the weakness of the other? What is the meaning of a therapeutic relationship in the face of chronic disease? What characteristics of physicians assist them in successfully working with patients with chronic illness? Can these characteristics be taught? How is success measured?

I have practiced clinical diabetes and metabolism in a community setting and I have elected not to be a superspecialist. A patient who comes in "not feeling well" with fever, high blood sugars, and a silent abscess in a neuropathic foot is taken into the clinical operating room and has the abscess opened and drained. The child with diabetes and viral gastroenteritis who presents with mild ketosis and dehydration is not admitted directly to the hospital. Instead, the child and family stay in the clinic for 4 to 6 hours while the child receives intravenous fluids and insulin. If the child improves, he goes home; if not, he is admitted to the hospital. In either case, the family knows that we have tried to keep the child out of the hospital and are appreciative. Similarly, simple lacerations are repaired, simple fractures are splinted, pneumonia and upper respiratory infections are treated, paps are completed. Patients in our practice have diabetes and we practice general medicine for the diabetic. Writing insulin orders is easy; the care of the entire patient is the challenge. All illnesses have an impact on glucose regulation, and diabetes confounds most other illnesses. This is not the model of the university training program. This is a model of primary care for a specific subset medical population.

In contrast to these "wants" of diabetic patients, most endocrinologists practice consultative diabetology. Their focus is glucose regulation. They all claim to take care of patients. What they really do is review blood sugar logs, ask disease-specific closed-ended questions, adjust medication, and schedule the patient to return in 3 to 4 months. "Next!" This is the model they were taught by the university in their clinical outpatient rotation, and this is the model they perpetuate. This is the model that is disliked by patients.

Recently, a medical center has developed and is marketing to HMOs a computer-based program for managing diabetes. This program requires the entry of physical data, and then the computer electronically formulates the "ideal treatment plan" for sugar, lipid, and blood pressure control. No direct hands-on physician involvement; a nurse can run the entire diabetic clinic. Once again the university disease mode comes glaringly into play; for some, treating blood sugar is the same as treating a patient with diabetes.

Recently, I had the opportunity to question the author of one of these programs about some subtle issues that concerned me.

Q: What about diabetic foot care? A: We will send them to podiatrists.

Q: What about patients who suffer an acute myocardial infarction? A: The patients will be sent back to their primary care physician.

Q: What about noncomplaint patients with poor clinical outcomes? A: They will be sent to dietitians, social workers, and nurse educators.

Q: What about the cost of implementing a totally integrated long-term health care program? A: Silence.

Q: What would be the cost to a large HMO for your component of diabetic treatment? A: Approximately 36 cents per month per total enrollment.

Q: What would be the bottom line savings to the HMO for this program during the first two years of operation? A: Silence.

This model ignores the patient and concentrates on the risk factors of the disease. In clinical medicine, the evolution of diabetic complications generally follows a slow and progressive path until a critical level of dysfunction is reached. Then, either due to progression of the underlying disease or the addition of another stressor, the patient becomes severely ill. The gatekeepers often refer to specialists as a last-ditch effort, when all hell has broken loose. The gatekeepers claim that the complications were the natural evolution of the disease and not the result of inadequate

care. Why should they take the blame for an amputated limb when the disease is known to cause this complication? "The patient apparently was doing well until. ..."

Primary care physicians have the responsibility for delivering medical care to over 85% of all diabetic patients. They have the skill and training for good interview techniques and a track record for continuity of care for their patients. The negative is that many lack the knowledge and skill to properly manage patients with diabetes. As a group, they claim to know how to treat diabetes, yet even routine care of the patient with diabetes has been shown to be substandard. Retrospective clinical medical record reviews reveal that yearly urine analysis for microscopic proteinuria, a detector for early diabetic renal disease, is not performed. The common blood test, Glycohemoglobin A-1c, a measurement of glucose control for the past 4 months, is usually not ordered. If these test results are available, they are usually ignored. They are not used to assess the effectiveness of glucose control, nor are they used to aggressively modify the medical treatment plans.

For the past 8 years, the American Diabetes Association (ADA) has published recommendations for standards of care of the diabetic. Despite the widespread dissemination of this information, physicians fail to read and follow the guidelines. Few physicians attend lectures dealing with the daily delivery of quality diabetes care within their office practice; less will have an organized approach to the evaluation of the health status of their diabetic patients.

A glaring example of this poor medical care concerns the feet of patients with diabetes. Recognizing that the neuropathic insensitive foot will lead to foot ulceration, infection, and amputation, it has been the ADA's guideline for years that every physician taking care of a diabetic patient must examine the feet on each office visit. Despite these recommendations, a recent survey reveals that fewer than 15% of physicians caring for patients with diabetes request shoe and sock removal. Despite the ADA standards, there is no method of forcing physician compliance. Physicians within their medical offices are not held accountable.

How does one reconcile the differences between what is practiced on the clinical level within the primary care setting and the classic university model of consultative diabetology? I propose that it is time to bring about a dramatic shift in attitude and application of medical efforts in treating diabetes. Superspecialists working with diabetic patients have to relinquish their self-appointed role of "sugar shakers" and begin to take the responsibility of the total care of the patient. Clean hands physicians will have to come out from behind the security of their consultative desks and touch patients.

A new model for community-based diabetes care. The development of this model does not presuppose that all diabetic patients be transferred to the care of endocrinologists. This idea is unworkable because there are too many diabetic patients and too few endocrinologists who care for the total patient.

What is required is the establishment of treatment teams comprised of patient, primary care physicians, endocrinologists, nurse educators, dietitians, and social workers all working for the health of the patient. Turfing will have to stop. Primary care physicians will have to be educated and certified in the care of the diabetic patient. Physicians will have to demonstrate competency. It is time for the private office physicians to be subjected to quality review.

For example, we recently instituted insulin pump therapy in a 24-year-old woman with progressive renal failure. She was soon to require hemodialysis. The patient had been sent to me by her primary care physician as a last-ditch effort to control her blood sugars. She was frightened and totally physician dependent. Her doctor for the past 10 years had always insisted on total control over her diabetic life. He would tell her what to eat and how much insulin to inject. She was never to question his rules and orders. She felt manipulated, impotent, and enraged. Nothing that she was told to do was effective in controlling her blood sugars, and she was forbidden to manage her own diabetes. Her personhood apparently meant nothing to her doctor.

Our diabetic treatment team worked intensively with her as an outpatient. In three weeks, she learned modern dietary principles, insulin pump management skills, and a lot about herself. She finally had the opportunity to talk to people who listened and gave her respect. Her pride of self slowly emerged. She was now able to live and direct her own life. She felt empowered. Her blood sugars were now under excellent control, and she felt back in control of at least one aspect of her life. This patient's medical progress and psychological growth were important to the patient, and the physician.

When the diabetes is out of balance, look to the emotions and not just the body. Patients want to talk to their doctor. They want to be heard; to be understood; to be remembered. This takes time, skill, and the physician's commitment to the total patient, not only to the disease.

Clinical endocrinologists often lack psychological-based interview skills and fail to appreciate the impact of psychosocial issues on the life and health of the patient with diabetes. Endocrinologists will have to become comfortable with issues of emotional pain and conflict and sensitive to the clues that lead to understanding, not just prescribing.

Understanding requires that all physicians caring for patients with diabetes stop and listen to what and how patients tell their story. This process is different from just obtaining a medical history. It requires a dialogue. Closed-ended questioning is robotics: open-ended interview techniques require hearing, time, and patience.

Many physicians are not sensitive to the clues of emotional pain. When faced with the clinical problem of diabetes out of control, they fail to appreciate that in most instances, the patient is out of control of their own emotional life and that the sugar levels are just a reflection of this pain.

When physicians refer their noncompliant diabetic patients for psychology/ psychiatry consultation, they want the therapist to change the patient into a "good little diabetic." What these referring physicians get from the consultant is an unexpected and shocking picture of a patient in severe emotional pain and depression, a dysfunctional life with a patient's distorted sense of self, family relationships, and work performance.

To come to this understanding, the therapist had spent time listening, hearing, and feeling the responses from the patient. He or she asked simple questions honestly; and honestly listened to the answers. Often physicians will defensively remark that this takes a lot of time, time they do not have to spend with any one patient. These physicians fail to appreciate the fact that they have a longitudinal relationship with a patient. They have many opportunities to renew a dialogue and to listen to responses. Physicians have the additional benefit of the "laying on of hands," which fosters both intimacy and an opportunity to continue the dialogue. Physicians must listen and hear. They must be aware of what the patient is saying and when they say it. Often the patient's first remark as the physician enters the examining room or the last remark as the patient leaves gives major clues to many of the important troubling issues.

Private time between patient and physician must be respected and protected. Interruptions by telephone calls and knocks on the door destroy any opportunity to develop an intense personal dialogue. Patients feel that these interruptions demonstrate that they are not important to the physician.

Often, well-intentioned physicians fail to give patients "alone time." Frequently, family members hovering around the patient in the examination room become a major barrier to a physician-patient relationship. These family members mean well. Yet, often a spouse will answer a question posed to the patient without allowing their significant other to speak. For the competent patient, this is the ultimate destroyer of patient-physician intimacy. Parents, spouses, and even children of elderly parents often feel they have a right to be present during these times. The physician has a responsibility to the patient to request privacy even to the consternation of the other interested parties. Recently, a colleague of mine reported that he had asked a young, pregnant diabetic woman about prior pregnancies. She hesitantly reported three therapeutic abortions. Her husband who had accompanied her into the examination room gasped; he had believed that this pregnancy was her first. The doctor-patient relationship was doomed, and possibly also the marriage. Where is the physician's sensitivity, compassion, caring?

Intimacy and the capacity for growth. Throughout this discussion, I have flirted with a very difficult concept, one that often makes physicians uncomfortable. What are the meanings and implications of intimacy within the medical clinical setting? It has been suggested that the word is too powerful, that it implies equal vulnerability and equal sharing, that it has sexual connotations, that it lays bare the dangers of countertransference. Formal medical education has classically stressed the importance of objectivity and the maintenance of professional distance. "Clinical judgment must remain pure and not become clouded with emotionality." How should clinical instructors interact with their patients within their own private medical offices. Successful physicians practice the art of medicine, an art that uses science, technology, objectivity, and sensitivity as tools and not ends in themselves.

The human touch, the listening eyes, the body movements of involvement transcend the space between the afflicted (pained) and the physician. The initial formal relationship will change, and it may do so rapidly. The care giver gives and the patient takes. The physician's commitment to medicine becomes translated by the patient into a commitment to self. Terms like "dedicated," "involved," "caring," and "committed" each describe a portion of the physician-patient relationship, yet none reflects the intensity. Patients want a physician with all of these attributes because they are hurting, frightened, and vulnerable. They look at the physician and see a wise and knowledgeable source of information and remedy, a friend who has their best interests at heart, a parental figure who will take away

their pain, and a magician who will banish evil and make them well.

Recently, I sat with a woman who was dead but would not die. She was 34 years old and had been diabetic since the age of 10. She was blind and suffered unrelenting pains of peripheral neuritis. She had diabetic gastroparesis. One night, her stomach would not empty itself of her dinner and she suffered a severe brain-destroying hypoglycemic reaction to her self-injected insulin. Her frontal and midbrain infarcted, and she was in a persistent vegetative state.

This woman and her family had been patients of mine for 5 years, and each of them had often talked individually about their own philosophies of life and death. An intimate relationship had developed in which I clearly understood their advanced directives and their spiritual values. These conversations were held over time, not because any one of us had expected catastrophe, but because it is important and is part of a patient/physician relationship.

They all grieved and prayed for a miracle of awakening, and then the inevitable meeting was held to discuss termination of medical treatment. This was a quiet meeting. This was a time to reflect on the woman's good times and the recent years of suffering. Everyone had an opportunity to speak and listen to the other family member's pain of decision making. At the end of the meeting, her husband embraced me and said, "We love and respect you for all the years of dedication, care, and understanding. Are you OK, Doc?"

My patients know a lot about me. How can one interact with another human being on a weekly or monthly basis and not share self? Even if I didn't voluntarily share my feelings, my patients quickly understand the changes in my body language and tone of voice. It is time for physicians to rediscover the value of intimacy so that both the patient and the doctor will benefit from a caring relationship. Scientific knowledge, diagnostic acumen, and therapeutic proficiency are imperative for good medical care, but it is the addition of humanism and understanding that enables the doctor to evolve into a physician. The care of the chronically ill demands a reevaluation of classical medical models of treatment. It is hoped that the university teaching philosophy will change to embrace issues and methods that are vital for those patients who will never be well.

Reproduced with permission of the copyright owner. Further reproduction or distribution is prohibited without permission.